UNITED STATES DISTRICT COURT
THE EASTERN DISTRICT OF NORTH CAROLINA
WESTERN DIVISION
CIVIL CASE NO.: 5:16-cv-854

Disability Rights North Carolina, North Carolina's Protection and Advocacy System, *Plaintiff,* v. Richard Brajer, Secretary of the North Carolina Department of Health and Human Services, in his official capacity; *Defendant.*	**COMPLAINT FOR DECLARATORY & INJUNCTIVE RELIEF**

Plaintiff, Disability Rights North Carolina brings this action under the Medicaid Act on behalf of Medicaid eligible children under the age of 21 who have complex unmet behavioral health needs. Plaintiff alleges as follows:

I. PARTIES

A. The Plaintiff

1. Plaintiff Disability Rights North Carolina is a North Carolina non-profit corporation that is a "person" authorized to seek legal and equitable relief. Disability Rights North Carolina serves as the federally mandated protection and advocacy (P&A) system for people with disabilities in North Carolina. Pursuant to this designation, Disability Rights North Carolina serves as the agency to implement, on behalf of the state of North Carolina, the following programs: Protection and Advocacy for Individuals with Developmental Disabilities, 42,

U.S.C. §§ 15041-15045, Protection and Advocacy for Individuals with Mental Illness, 42 U.S.C. §§ 10801-10851, and Protection and Advocacy of Individual Rights, 29 U.S.C. § 794e. Disability Rights North Carolina has the statutory authority to pursue legal, administrative, and other appropriate remedies to protect and advocate for the rights and interests of people with disabilities.

2. Specifically, Disability Rights North Carolina brings this action on behalf of children who are Medicaid eligible, under the age of 21 and who have both chronic mental health conditions and developmental disabilities. These children need adequate, effective and appropriate services to correct or ameliorate their conditions, including comprehensive assessments, home and community-based behavioral support services provided by trained professionals, psychiatric and other clinical services, crisis services, and case management services - all of which are covered services for children and youth under the Medicaid Act.
3. The federal regulations governing the P&A network provide that each P&A is authorized to bring "lawsuits in its own right to redress incidents of abuse or neglect, discrimination and other rights violations impacting on individuals with mental illness and when it appears on behalf of individual plaintiffs or a class of plaintiffs for such purposes." 42 C.F.R. § 51.6(f).
4. Disability Rights North Carolina represents the interests of, and is accountable to, members of the disability community. For example, Disability Rights North Carolina is required by federal statute to maintain a governance structure that ensures that the P&A is responsive to the disability community. 42 U.S.C. § 15044(a) (requiring that a majority of board members be people with disabilities or their families).
5. Disability Rights North Carolina must, and does, maintain an advisory council on mental health matters to "advise the system on policies and priorities to be carried out in protecting

and advocating the rights of individuals with mental illness." 42 U.S.C. § 10805(a)(6). The chair and at least 60% of the council members must be mental health care consumers or family members of mental health care consumers. *Id.*

6. Disability Rights North Carolina conducts annual surveys of the disability community to determine the specific areas of advocacy on which the organization will focus. Disability Rights North Carolina is required to, and does, seek public comment on the direction of its work and periodically conducts listening sessions across the state to identify community concerns.

7. As a result of Disability Rights North Carolina's organizational structure, its governance and leadership, its connections with its constituents, and its involvement with the disability community generally, people with disabilities, including people with mental illness, have a strong voice in and a direct influence on the work of the organization.

8. For each of the past five (5) years, the advisory council and the board of directors of Disability Rights North Carolina have recommended that the organization adopt as one of its priorities the delivery of adequate mental health services for children. As a result of this recommendation, the attorneys of Disability Rights North Carolina have represented dozens of children who are not receiving adequate and appropriate mental health services.

9. In the absence of relief in this matter, dually diagnosed children with complex mental health needs in North Carolina who are eligible for mental health services, and their families, will remain unaware of the availability of adequate and appropriate mental health services and will not receive appropriate mental health care.

10. Medicaid-eligible children under the age of 21 who have dual or multiple diagnoses have suffered injuries, or will suffer injuries, that would allow them to bring suit against the

Defendant. Although individual children with complex mental health needs have standing to bring this action, it is the unique duty of Disability Rights North Carolina to bring this action to remedy a wrong that affects a broad range of dually diagnosed children with complex mental health needs who would not otherwise be in a position to bring individual actions. Disability Rights North Carolina seeks the implementation of remedies that will benefit all eligible dually diagnosed children with complex mental health needs and not particular individual remedies.

11. Disability Right's principal place of business is in Raleigh, North Carolina.

12. Disability Rights North Carolina seeks prospective injunctive relief ordering the Defendant to provide the necessary community-based screening, assessment and treatment services that dually diagnosed, Medicaid-enrolled children are entitled to receive in accordance with federal law.

B. The Defendant

13. The Defendant, Richard Brajer, is the Secretary of the North Carolina Department of Health and Human Services (DHHS). As such, he is responsible for the supervision and oversight of DHHS's programs and contractual arrangements for implementing those programs. DHHS is designated as the "single state agency" with direct responsibility for administering and implementing the Medicaid program consistent with the requirements of the federal Medicaid Act. 42 U.S.C. § 1396a(a)(5); N.C. Gen. Stat. § 108A-54. Secretary Brajer is sued in his official capacity.

II. JURISDICTION & VENUE

14. Jurisdiction is conferred on this Court by 28 U.S.C. § 1331, which provides for original jurisdiction over all civil suits involving questions of federal law, and 28 U.S.C. §§ 1343,

which grants this Court original jurisdiction in all actions authorized by 42 U.S.C. § 1983 to redress the deprivation under color of state law of any rights, privileges, or immunities guaranteed by the U.S. Constitution and Acts of Congress.

15. This Court has jurisdiction over this action for declaratory relief pursuant to 28 U.S.C.§ 2201 and Rule 57 of the Federal Rules of Civil Procedure. Injunctive relief is authorized by 28 U.S.C. § 2202, 42 U.S.C. § 1983, and Rule 65 of the Federal Rules of Civil Procedure.

16. Venue for this action lies in this district pursuant to 28 U.S.C. § 1391(b), because a substantial part of the events or omissions giving rise to Plaintiff's claims is occurring here and the Defendant may be found here.

III. The Mental Health Crisis in North Carolina

17. Disability Rights North Carolina brings this action on behalf of children who are Medicaid eligible, under the age of 21 and who have chronic mental health conditions and developmental disabilities. These children need adequate, effective and appropriate services to correct or ameliorate their conditions, including comprehensive assessments, home and community-based behavioral support services provided by trained professionals, psychiatric and other clinical services, crisis services, and case management services.

18. The Defendant is failing to provide these children with appropriate mental health services to screen, diagnose and/or treat their conditions as required by the Early and Periodic Screening, Diagnostic and Treatment (EPDST) provisions of Title XIX of the Social Security Act (Medicaid Act). 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

19. Children with complex mental health needs are often required to leave their families and communities to receive services, usually in restrictive, institutional settings. Many children with complex mental health needs have been hospitalized because of the lack of necessary

community-based services. These children are being harmed because they are not receiving medically necessary community-based services.

20. This escalating crisis is primarily due to the Defendant's failure to address persistent deficiencies in the system of care and make available the medically necessary services and supports needed to correct or ameliorate the dual and multiple diagnoses for Disability Rights North Carolina's clients and those similarly situated.

21. The inappropriate and excessive use of psychiatric hospital beds, and the attendant backlog of admissions, have forced the Defendant and his agents, the Local Management Entities/Managed Care Organizations (LMEs/MCOs) to transport children with dual and multiple diagnoses far from their homes and many times out of state as these are the only options for this Medicaid population. Being treated far away from home or out of state further complicates and delays the child's discharge to an appropriate community-living arrangement.

A. The Crisis for Disability Rights North Carolina Clients

Client O.B.

22. Client O.B. is a fifteen-year-old adolescent from Raleigh, North Carolina and a Medicaid recipient since age six. O.B. has a moderate to severe intellectual disability, autism, and intermittent explosive disorder. She is nonverbal. In 2010, she started receiving services through the Innovations Waiver, a community-based program for children with intellectual developmental disabilities.

23. O.B. could live a meaningful life in the community with the proper services and supports that are appropriate to her needs.

24. O.B. has been shuffled between dozens of hospitalizations and other institutional settings during the course of her childhood. She has not been provided with adequate, sustained services that she needs to develop. As detailed below, this failure of Defendant's service system has resulted in long-term physical and developmental harm to O.B.

25. O.B. has a history of aggression, tantrums, self-injury, and property destruction. At the age of ten, she was hospitalized at Bryn Marr, a psychiatric hospital, for approximately two weeks. This was her second admission to this facility. After a brief stay there, she was admitted to the Partners in Autism Treatment and Habilitation (PATH) program at the Murdoch Center (hereinafter Murdoch) in September 2010. O.B. was placed at Murdoch because she was having psychotic episodes and had some aggressive behaviors at school and home. She was at Murdoch until March 2012.

26. Between March 2012 until late August 2014, O.B. struggled along and remained in the community with inadequate services.

27. In September 2014, O.B. was admitted to Strategic Behavioral Center (hereinafter Strategic). While at Strategic, she had some regression due to lack of appropriate care. For example, rather than provide her with sanitary napkins, she was placed in pull-ups during her menstrual cycle. As a result, she regressed and began urinating in the pull-ups. O.B. was discharged from Strategic after one week.

28. The day after her discharge, O.B. returned to school without adequate supports or transition services. Around 8:55 a.m., the school called her mother to come pick her up. O.B. became physically aggressive in the school cafeteria when her mother came to pick her up. Three staff members and her mother had to restrain her. O.B. returned to school on September 18, 2014, again without needed supports, and was again sent home shortly after her arrival.

29. O.B. returned to Strategic on or about November/December 2015. She was unable to be stabilized at Strategic. She applied to the Therapeutic Respite Addressing Crisis for Kids (TRACK) program at Murdoch; however, she was denied acceptance to the program because Strategic inaccurately indicated that O.B. was stable and there was an Alternative Family Living (AFL) provider willing to accept her. She was accepted into the TRACK program only after attorney intervention. On or about February 10, 2015, she was transferred from Strategic to Murdoch.

30. At Murdoch, it was suspected that O.B. was being over-medicated. She was drooling, having problems walking, and lost eight pounds due to swallowing issues. Initially, she was scheduled to be discharged on or about March 10, 2015; however, her placement in TRACK was extended to the full 45 days of the program.

31. In March 2015, O.B. was placed at an AFL provider upon her discharge from Murdoch, again, without adequate additional supports. Within 24 hours of her discharge from the Murdoch Center, she was involuntarily committed at Western WakeMed Emergency Department (WakeMed) by law enforcement. She was in the emergency room for eight days because the hospital did not have any available beds in the psychiatric unit.

32. On or about April 13, 2015, O.B. was discharged from WakeMed and sent to Broughton Hospital in Morganton, North Carolina. Broughton is a state psychiatric hospital. After being at Broughton for about a day, a bed became available at Central Regional Hospital in Butner, North Carolina. Central Regional Hospital is another state psychiatric hospital. She was then transferred to Central Regional Hospital.

33. O.B. was at Central Regional Hospital for about one month. On or about May 2015, O.B. was transferred to Cumberland Hospital, a psychiatric residential treatment facility located in Virginia.

34. In January 2016, O.B. returned home from Cumberland Hospital. While at Cumberland Hospital, she lost her eligibility for Innovations Waiver services. She was at home for about two weeks without adequate services and supports when she had an outburst and became aggressive. The police were called. O.B. was taken to WakeMed where she stayed for about two weeks awaiting an available bed.

35. In February 2016, O.B. was discharged from WakeMed. The worker who was supposed to meet O.B. at the hospital failed to arrive. The worker was supposed to develop a crisis plan if O.B. was to wake up during the night. Upon her release, she was to receive a one-on-one worker during the time she was awake. Staff was to leave when she fell asleep and return before she awoke in the morning. Eventually, a worker did come to the home. The worker went with O.B. and her mother to the pharmacy to fill O.B.'s prescription medications. While the worker was in the pharmacy, O.B. had an outburst when she was left in the car with her mother. She destroyed the back car seat, papers, and any other items she could get in her hands. Her mother had to go into the pharmacy to get the worker to help calm O.B.

36. The next day, the one-on-one worker took O.B. to Planet Fitness, a gym. O.B. became upset and hit and pulled the hair of two individuals. In the absence of any designated mobile crisis services, the worker called the police. O.B. was handcuffed and restrained until EMS arrived. She was initially taken to WakeBrook, a crisis stabilization center; however, the facility was at capacity. She was taken back to WakeMed. Her mother requested that an

application be submitted for the TRACK program at Murdoch. However, O.B.'s care coordinator told her that she could not make the referral because O.B. was no longer in crisis.

37. In March 2016, O.B. was discharged from WakeMed. Four workers were sent to her home to assist with the transition. At approximately 4:00 p.m., all the workers left because they had tickets to attend a basketball tournament in Charlotte, North Carolina. O.B. was authorized to receive two workers to be with her at one time; however, only one worker arrived at approximately 5:00 p.m. to stay with her until 1:00 p.m. The following day, two workers arrived at approximately 1:00 p.m. and stayed until about 6:30 p.m. During that time, O.B. became upset, and the staff called the police. While the staff was away, she attacked her mother. She was taken to WakeBrook, a crisis stabilization center, but it could not meet her needs. Once again, she was sent back to WakeMed.

38. In March 2016, O.B. was discharged from WakeMed under a clinician's order for her not to return home. She was again admitted to the TRACK program at Murdoch on or about March 3, 2016 for 28 days. Community placement could not be found for O.B. upon her discharge from Murdoch. Murdoch would not extend her placement. It determined that it was clinically inappropriate for her to continue to stay at Murdoch just because there was not an available placement for her to return to the community.

39. In April 2016, O.B. was discharged from Murdoch and returned home with her mother as an appropriate community placement could not be found for her. She was authorized to receive 24 hour two-on-one coverage; however, she only received two-on-one coverage from 9 a.m. to 9 p.m. From 9 p.m. to 1 a.m., she received one-on-one coverage and she had no coverage from 1 a.m. to 9 a.m. The provider told O.B.'s mother that two-on-one staffing is not allowed. During her second week at home, the police were called after two of the workers got

into an argument. O.B. became upset after witnessing the argument, and her mother could not calm her down. Her mother called the police, EMS, and North Carolina Systemic, Therapeutic, Assessment, Respite and Treatment (NC START) program. By the time she calmed down, O.B. had destroyed the kitchen table, pulled the television off the wall and thrown it through the window.

40. O.B. was transferred to a respite provider who was in the process of being licensed as an AFL provider for children. While at this respite provider, O.B. was allegedly severely beaten. On or about June 13, 2016, she was admitted to pediatric intensive care unit (PICU) at the WakeMed. She had stale blood in her abdomen, two broken bones in her back, injuries to her eye, and bruises around her eyes and forehead. O.B. had to have surgery to have a part of her intestine removed due to the damage she sustained. She had to wear a colostomy bag until she was discharged in early August, 2016 from WakeMed. O.B. was then admitted to Cumberland, a psychiatric residential treatment facility in Virginia. She was transferred to Cumberland for additional medical recovery for the injuries she sustained.
41. O.B. has experienced repeated cyclical hospitalizations and residential placements.
42. During O.B.'s numerous transitions, her mother has struggled to try to link her to the appropriate medical, educational, and community services.
43. O.B.'s family has attempted to access the right mix of services for her, but has not been successful.
44. O.B.'s treatment teams have repeatedly found that she could benefit from the medically necessary services required by the EPSDT provisions of the Medicaid Act.
45. For months, the Defendant has been aware of O.B.'s inadequate services.

Client K.B.

46. Client K.B. is a seventeen (17) year old Medicaid recipient from Huntersville, North Carolina. K.B. has autism, an intellectual disorder, Smith-Magenis Syndrome, sleep disorder, conduct disorder, and impulse control disorder. As a result of his condition, he exhibits a number of behaviors, including physical aggression, property destruction, self-injurious behaviors, tantrums, elopement, and inappropriate verbal behavior.

47. From 2008-2011, K.B. had approximately seven cyclical hospitalizations at Carolinas Medical Center-Randolph (CMC-Randolph) in Charlotte, NC for aggressive behaviors. Upon each discharge, he was sent home without adequate services. K.B.'s parents reached out to many providers with the LME/MCO, but no appropriate services were identified.

48. In October 2011, K.B. was admitted to the TRACK program at Murdoch for twenty-nine (29) days because he had not received community-based care. He was discharged about a month later without adequate transition or ongoing services in place.

49. About three weeks later, K.B. was readmitted to the TRACK program for forty-five (45) days for aggression, destructive behaviors, inappropriate verbal behavior, unsanitary behavior, inappropriate masturbation and stripping due to the lack of appropriate care.

50. In February 2012, K.B. was admitted to the TRACK program again for forty-five (45) days due to the lack of appropriate care.

51. In March 2012, K.B. was again discharged from Murdoch because Murdoch would not grant an extension to stay there until a placement was secured.

52. K.B. transitioned to Cumberland Hospital Neurobehavioral residential program in Virginia. K.B. was in the program for one hundred and thirteen (113) days.

53. On July 12, 2012, K.B was transitioned again to the PATH program at Murdoch. He was admitted for treatment of behavior problems including physical aggression and self-injurious behaviors.

54. He was discharged from the PATH program in March 2015 to a Community Alternatives group home in Cleveland County. On his first day of returning to school, he was suspended. He pulled a water fountain from the wall, urinated on classmates' backpacks, broke a window, and cut himself.

55. Less than two (2) weeks after his transition to a community group home, he locked himself in his bedroom for five (5) hours. He pulled down the ceiling fan, threatened his roommate, and pulled a metal rod from his closet. Later that night, he ran away from the group home. The police and EMS were both called. K.B. was found in a wooded area. He was administered Haldol. K.B. was taken to the emergency room at the local hospital. During the ambulance ride, he destroyed the inside of the ambulance. Plans were made to admit him again to Murdoch.

56. Soon thereafter, K.B. was admitted to the TRACK program for twenty-eight (28) days. K.B. was scheduled to be discharged on or about July 5, 2015; however, there was no community placement available for him. Therefore, his placement at Murdoch was extended and he was transferred to the Murdoch PATH group home.

57. K.B. was again ready for discharge on or about September 3, 2015. His treatment team recommended a group home with community-based behavioral health services. However, no providers in North Carolina would accept him due to his aggressive behaviors. As a result, Pine Grove in Elgin, South Carolina was recommended as a residential placement for K.B.

However, on or about October 16, 2015, K. B's family was informed that there was a funding issue with Pine Grove, and K.B.'s admission could not be authorized.

58. In January 2016, K.B.'s parents were given another list of potential in-state residential providers. When his parents met with providers and explained K.B.'s high level of needs, many of the providers explained that they could not meet his needs.

59. In February 2016, RHA, a provider of residential services, participated in a treatment team meeting discussion about possible options for K.B. because of RHA's history of working with young adults similar to K.B. Thereafter, RHA presented a proposal with two community-based options for K.B. Option 1 proposed RHA creating a new 4 bed home in the Orange County area. Residents will have full access to the community to (work, socialize, access transportation, have avenues for education and for residents to have opportunities to contribute as a volunteer in the community support each person's faith as desired and to be accepted as a neighbor and a friend). Option 2 proposed a four bed home in Maxton, North Carolina with a similar setup as that described in Option 1.

60. No decision has yet been made on the RHA proposal.

61. In April 2016, ten (10) placement options were discussed for K.B. at the treatment team meeting. Only one was in North Carolina. It was a group home that has only limited opportunity for community integration, and its residents are forty (40) to fifty (50) years old. Another was a psychiatric residential treatment facility in Atlanta, Georgia. Several others were not appropriate or could not meet his needs. One out-of-state placement in Massachusetts seemed as though it may be appropriate; however, it did not accept Medicaid.

62. As of the date of this Complaint, K.B. continues to reside at the Murdoch Center where he waits for appropriate community placement.

63. During K.B.'s numerous transitions, his family has struggled to try to link him to the appropriate services without success.

64. K.B. could benefit from the medically necessary services required by the EPSDT provisions of the Medicaid Act. For months, the Defendant has been aware of K.B.'s inadequate services.

IV. THE MANDATES OF THE MEDICAID PROGRAM

A. *The Federal Medicaid Program*

65. The Medicaid program, authorized and regulated pursuant to Title XIX of the Social Security Act, is a joint federal-state medical assistance program for certain groups of low-income persons. 42 U.S.C. § 1396-1396w. One of the purposes of the Medicaid program is to provide services to help such families and individuals attain or retain capability for independence of self-care. *Id.* at § 1396-1.

66. At the federal level, the Medicaid program is administered by the U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services (CMS).

67. States are not required to participate in Medicaid, but once a State decides to participate in Medicaid, it must comply with the requirements imposed by the Act itself and by the U.S. Secretary of the Department of Health and Human Services.

68. North Carolina has chosen to participate in Medicaid.

69. States are reimbursed by the federal government for a portion of the costs of providing Medicaid benefits.

70. North Carolina receives approximately sixty-six cents in federal reimbursement for every dollar it spends on Medicaid services. 42 U.S.C. 1396d(b), 1101(a)(8), 42 CFR 430 and 42 CFR 447(Notice).

71. Federal law requires participating States to provide certain mandatory services. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a). One mandatory service is Early and Periodic Screening, Diagnostic and Treatment (EPSDT) for Medicaid-eligible children under age 21. 42 U.S.C. §1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

72. The purposes of EPSDT are to ascertain children's physical and mental impairments, and to arrange for or provide such health care, treatment, or other measures to treat or ameliorate impairments and chronic conditions discovered through EPSDT screenings. The policy underlying the EPSDT mandate is to prevent illness as well as to ensure that health problems are comprehensively diagnosed and then treated as soon as they are detected, before they become more complex and their treatment costlier.

73. The goal of EPSDT is to "assure that individual children get the health care they need when they need it-the right care to the right child at the right time in the right setting." CMS EPSDT-A Guide for States: Coverage in the Medicaid Benefit for Children and Youth 1 (June 2014), https://www.medicaid.gov/.../downloads/epsdt_coverage_guide.pdf (last visited May 6, 2016)

74. EPSDT consists of the following requirements:

- Informing all persons in the State who are under the age of 21 and who [are] eligible for medical assistance of the availability of early and periodic screening, diagnostic and treatment services as described in Section 1396d(r);

- Providing or arranging for the provision of medical, vision, hearing and dental screening services in all cases where they are requested;
- Arranging for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment when such child health screening services indicate a need. 42 U.S.C. § 1396(a)(43).

75. Under EPSDT, States must provide the services listed in 42 U.S.C. § 1396d(a) when necessary to "correct or ameliorate" an eligible child's physical or mental condition. 42 U.S.C. § 1396d(r)(5).

76. Among the services listed within § 1396d(a), and thus within the EPSDT scope of mandatory benefits for children, are:

- medical or other types of remedial care furnished by licensed practitioners within the scope of their practices, 42 U.S.C. § 1396d(a)(6); 42 C.F.R. § 440.60;
- home health care services, including nursing services, home health aide services, and medical equipment and supplies, §1396d(a)(7) and 42 C.F.R. §440.70;
- physical and related therapies, including services for individuals with speech, hearing, and language disorders, 42 U.S.C. § 1396d(a)(11); 42 C.F.R. § 440.110;
- private duty nursing services, 42 U.S.C.§ 1396d(a)(8); 42 C.F.R. §440.80
- rehabilitative services "recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under State law, for maximum reduction of physical or mental disability and restoration of a Medicaid beneficiary to his best possible functional level," 42 U.S.C. §1396d(a)(13) and 42 C.F.R. §440.130(d);
- preventive services "recommended by a physician or other licensed practitioner of the healing arts acting within the scope of authorized practice under State law to prevent

disease, disability, and other health conditions or their progression; prolong life; and promote physical and mental health and efficiency," 42 U.S.C. § 1396d(a)(13); 42 C.F.R. § 440.130(c) (as amended July 2013).

- personal care services in non-institutional settings such as the home, 42 U.S.C. § 1396d(a)(24); 42 C.F.R. § 440.167;
- case management services furnished to assist beneficiaries "who reside in a community setting or are transitioning to a community setting, in gaining access to needed medical, social, educational, and other services," 42 U.S.C. §§ 1396d(a)(19), 1396n(g); 42 C.F.R. §§ 440.169; 441.18; and
- other medical and remedial care recognized by the Secretary of the U.S. Department of Health and Human Services, including transportation to secure medical examinations and treatment for a beneficiary and travel expenses that include the cost of meals and lodging in route to and from medical care, and while receiving medical care; and the cost of an attendant to accompany the beneficiary, if necessary, and the cost of the attendant's transportation, meals, lodging, and, if the attendant is not a member of the beneficiary's family, salary; 42 U.S.C. § 1396d(a)(29); 42 C.F.R. § 440.170.

77. In order to provide these required services, the Medicaid agency must make available a variety of individual and group providers qualified and willing to provide EPSDT services. 42 C.F.R. § 441.61(b).

78. While the State may adopt managed care concepts and contract with entities to oversee the delivery of services and to arrange services through provider networks, the State remains responsible for ensuring compliance with all relevant Medicaid requirements, including the mandates of EPSDT. 42 U.S.C. §§ 1396a(a)(5); 1396u-2.

79. States must provide Medicaid benefits to all eligible individuals with reasonable promptness. 42 U.S.C. § 1396a(a)(8); 42 C.F.R. § 435.930(a).

80. EPSDT treatment services must be initiated in a timely manner, as the individual needs of the child require and consistent with accepted medical standards. Federal regulations require that treatment should be initiated no more than six months after the request for screening services. 42 C.F.R. § 441.56(e).

B. *The North Carolina Medicaid Program*

81. The North Carolina Department of Health and Human Services (DHHS) is designated as the single state Medicaid agency responsible for the administration and supervision of North Carolina's Medicaid Program consistent with the Medicaid Act. DHHS has delegated chief responsibility for administering the federal Medicaid program to the Division of Medical Assistance (DMA).

82. The North Carolina Innovations Waiver is a Medicaid waiver program for individuals with intellectual/developmental disabilities. Individuals served under the Innovations Waiver are expected to be able to live in the community when supported with appropriate services.

83. As permitted by the Medicaid program, DHHS currently contracts with seven local managed entities/managed care organizations (LMEs/MCOs) to provide behavioral health and mental health services to North Carolina Medicaid recipients. Pursuant to the DHHS contract with these LME/MCOs (Smoky Mountain Center (Vaya Health), Partners Behavioral Health Management, Cardinal Innovations, Trillium Health Resources, Eastpointe, Alliance Behavioral Healthcare, and Sandhills Center), DHHS pre-pays the LME/MCOs on a per-member/per-month (also known as capitation) basis to deliver behavioral health services to

enrollees, including all EPSDT services to children with behavioral, emotional, or psychiatric impairments.

84. Medically necessary community-based services, involve trained behavioral support staff members who support the child in her/his natural or foster home, and in any other educational, after school, or treatment setting where the child spends part of her/his day. For example, as medically necessary, qualified staff should be consistently and routinely available for as long as necessary each day to treat or ameliorate the child's behavioral, emotional, or psychiatric condition. For some children with intensive needs, behavioral support staff members are provided up to twenty-four hours a day and seven days a week.

85. Medically necessary community-based services can also include psychiatric and other clinical services to complement the ongoing, trained behavioral support staff who assist the child at home, in school, after school, and at other times. These additional supports focus on discrete clinical and other daily living issues, such as, *inter alia*, the development of an individualized treatment plan, the creation and implementation of a special behavioral plan, the supervision and direction of the behavioral support staff, the provision of support therapies, the assessment and administration of medication, and the coordination and monitoring of medically necessary community-based services through an interdisciplinary team.

86. Medically necessary community-based services also incorporate certain other supports to achieve desired outcomes. Professionally adequate assessments are essential to determine the type, level, and intensity of treatment and support services that an individual child needs, particularly where the child has complex or difficult-to-treat behavioral or emotional impairments. Crisis services must be available to come to the home and offer clinically

intensive interventions in the event of a mental health crisis which places the child at risk of hospitalization.

87. Finally, case management is a pivotal element of the program which usually refers the child to screening agencies and medically necessary community-based service providers and then ensures that home and community-based services meet all of the child's individual behavioral and mental health needs by identifying, coordinating, and monitoring the array of supports and staff that allow the child to remain in the community.

88. The Defendant has not included medically necessary community-based services, as described above, as part of the North Carolina's Medicaid program nor has he provided it as a covered EPSDT service. Instead, the Defendant, through LME/MCOs, customarily provides time-limited, non-intensive, behavioral health interventions to Medicaid eligible children in their homes through one specific service: Intensive-In-Home services (IIH).

89. IIH is intended to reduce presenting psychiatric or substance abuse symptoms, provide first responder intervention to diffuse current crisis, ensure linkage to community and resources, and prevent out-of-home placement for children.

90. IIH services normally are offered for ninety (90) days or less, even when long term, home-based treatment is necessary. IIH services generally are delivered for approximately six to eight hours a week, and they are designed to address acute crises or short-term conditions where a child is at imminent risk of hospitalization or after being discharged from a hospital. IIH services ordinarily are not prescribed for multiple days per week. Most IIH programs do not have the capacity or professional staff to provide sustainable medically necessary community-based supports to children who are dually diagnosed. When IIH services have

proven to be ineffective, no other services are generally available if the child still needs continued home based supports.

91. Because of the rigid limitations in the design and implementation of the IIH program models, the Defendant's Medicaid program does not provide meaningful access to medically necessary community-based services for the neediest and most vulnerable dually diagnosed children with behavioral, emotional, or psychiatric conditions.

92. Many of Disability Rights North Carolina's individual clients have been authorized to receive IIH service multiple times. The service has been found to be ineffective and does not meet the long-term treatment needs of these individuals and those in similar situations in the way it is currently delivered.

93. Despite its over-reliance on ineffective IIH, the Defendant has the means to deliver effective community based services to children with complex mental health needs.

94. Hundreds of children with behavioral, emotional, and/or psychiatric and co-occurring intellectual disabilities in North Carolina desperately need, but are not receiving, medically necessary services in their communities. This crisis is confirmed by gap analysis reports prepared by the LMEs/MCOs and reported in multiple media articles.

95. The Defendant regularly fails to inform or explain to Medicaid beneficiaries the services that may be available to correct or ameliorate their conditions.

96. Often times, parents are given verbal denials for services requested, thereby thwarting their opportunity to appeal the decision in accordance with the Medicaid regulations because they are not given written notice of their right to do so.

97. The Defendant's lack of planning, inadequate funding and administrative and policy making decisions have failed these children and caused them to go without medically necessary

community based wraparound services to prevent unnecessary hospitalizations, institutionalizations, out-of- home and out- of- state residential placements.

98. The Defendant's administration of the service system for children and adolescents with dual or multiple diagnoses causes children with complex mental health needs to go without medically necessary community-based wraparound services.

99. The failures of the Defendant's system to accommodate the needs of children with dual or multiple diagnoses has led to costly and unnecessary hospitalizations and institutionalizations for children with complex mental health needs.

100. Disability Rights North Carolina has provided legal representation to hundreds of children with dual and multiple diagnoses and obtained individual relief in some of the cases. However, the systemic failures remain unaddressed.

V. LEGAL CLAIMS

Count I Medicaid – Early and Periodic, Screening, Diagnostic and Treatment (EPSDT)

101. Plaintiff Disability Rights North Carolina re-alleges and incorporates by reference the allegations contained in all the preceding paragraphs.

102. The Defendant is failing to inform, assess, screen, and provide or arrange necessary EPSDT behavioral and mental health services, including community based services which are necessary to correct or ameliorate their behavioral, emotional, or psychiatric conditions, in violation of 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 136d(a)(4)(B), and 1396d(r)(5), which are enforceable by Medicaid eligible children pursuant to 42 U.S.C. § 1983.

Count II Medicaid – Reasonable Promptness

103. Plaintiff Disability Rights North Carolina re-alleges and incorporates by reference the allegations contained in foregoing paragraphs.

104. The Defendant has failed to provide medical assistance with reasonable promptness in violation of 42 U.S.C. § 1396a(a)(8), which is enforceable by Medicaid eligible children pursuant to 42 U.S.C. § 1983.

REQUEST FOR RELIEF

WHEREFORE, Disability Rights North Carolina respectfully request that this Court:

1. Issue a declaratory judgment holding that the Defendant has violated Title XIX of the Social Security Act in their failure to provide medically necessary EPSDT services to Medicaid-eligible children with behavioral, emotional, and psychiatric impairments.
2. Grant permanent injunctive relief requiring the defendant to:
    i. establish and implement policies, procedures, and practices for screening and evaluating Medicaid-eligible children under the age of 21 who have dual and multiple diagnoses to determine whether they are eligible for community based services medically necessary to treat or ameliorate their behavioral, emotional and psychiatric conditions and, if so, the extent of their community-based service needs;
    ii. establish and implement policies, procedures, and practices that are sufficient to ensure that the individual Medicaid-eligible children under the age of 21promptly receive the medically necessary community-based services they need to correct or ameliorate their conditions, including professionally-adequate assessments, crisis and case management services;
    iii. promptly assess the need for case management services by providing Medicaid-eligible children under the age of 21 with a case manager within sixty (60) days of

identification of a child with complex needs, in order to coordinate assessments and services for medically necessary community-based services.

iv. conduct professionally adequate assessments of all Medicaid-eligible children under the age of 21 who reside in private or public inpatient psychiatric facilities and DHHS' Residential Treatment Programs or Developmental Disabilities centers to determine whether medically necessary community-based services are medically necessary to treat or ameliorate their behavioral, emotional, or psychiatric conditions and, if so, ensure those services are provided;

v. initiate services as the individual child's condition requirement, within an outside limit of six months.

3. Require the Defendant to provide sufficient information on a quarterly basis to allow, Disability Rights North Carolina and the Court to monitor compliance with the Court's injunction and with the requirements of the Medicaid program.

4. Award the Plaintiff the costs of this litigation and reasonable attorneys' fees and costs.

5. Grant such further and other relief as may be just and proper.

BY ATTORNEYS,

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